

## **Using Surveillance Data to Achieve Elimination: Issues and Next Steps**

Childhood Lead Surveillance Meeting

September 24 - 26, 2002

St. Petersburg, Florida

Background: The Centers for Disease Control and Prevention (CDC) is committed to the 2010 national objective to eliminate childhood lead poisoning as a public health problem. CDC's childhood lead poisoning prevention programs (CLPPPs) play an essential role in achieving the national elimination goal. The CLPPPs all collect data that can be used to improve our ability to target and test children at greatest risk, to evaluate the effectiveness of case management in reducing children's blood lead levels and of prevention activities designed to prevent children from ever being poisoned, and to monitor our progress in attaining the elimination goal.

Purpose of Meeting: The purpose of this meeting was to share common concerns and suggestions about how we can improve surveillance systems at the national, state and local levels, and to provide tools to help meet increasing expectations for lead surveillance across the country.

Meeting Highlights: CDC convened a meeting with 2 representatives from each of the 60 CLPPPs to continue discussion of ways to improve the childhood lead poisoning tracking systems. While the meeting's focus was on data, CDC staff emphasized that surveillance data should support lead poisoning prevention efforts and that surveillance and program staff need to work together. CDC surveillance and program staff are working to improve the quality of the data and use the data to drive decisions. In the future there will be more emphasis on evaluating our activities, working with Medicaid partners to improve lead testing among high-risk children, and expanding our prevention efforts to include more primary prevention activities. Recently, CDC funded a total of \$1.2 million to about 15 CLPPPs to develop primary prevention.

Dr. Pat Meehan, Director, CDC Division of Emergency and Environmental Health Services, expressed his support of implementation and enhancement of primary prevention activities. He stated that when we go to the homes of children at risk for EBLs, we will work to address other environmental conditions that can affect health, and we will work to facilitate collaboration with partners from HUD, CMS and EPA. He advised that CDC will ask CLPPPs to develop elimination plans for their jurisdictions, including plans to work with key partners. Recently, Dr. Meehan met with Senator Reid's staff. He commented that there is strong support for preventing childhood lead poisoning. Senator Reid's staff requested advice on what is needed to accomplish our elimination goals.

BLs continue to decrease nationally due to policies banning use of lead. Since the 1990's the decreases have been smaller. Surveillance data show the risk of exposure to lead is not equally distributed across the nation. Children who are poor are at risk for being missed by the health care and even public health system--- data can help us reach them. When the participants were asked how many thought elimination as a public health problem was possible, there were few hands raised in agreement. If we strive to provide a comprehensive program and continually use existing data to assess our impact and improve our work, then we should see a large decrease in the number of children with EBLs. Data must be used to help identify children with EBLs; to evaluate and improve case management; and to develop and implement interventions to prevent kids from getting lead poisoning.

The Lead Branch is working with Battelle to upgrade the processing of the surveillance data CLPPPs submit to CDC to develop routine reports and expand data quality checks. CDC is working with other groups at CDC to move the lead tracking from STELLAR to NEDSS. NEDSS is a web-based system, most health departments will probably use it so there will be some support at the health departments; and NEDSS could help lead move to more frequent data submissions... semi-annually or even quarterly.

*Work Group Reports* – One of the outcomes of the conference calls with CLPPP staff in December 2001 was the formation of workgroup for two topics: data standards and data release. These work groups were coordinated by CDC staff and included members from several CLPPPs. The recommendations from these workgroups are important so CDC can distribute standardized information about CLPPPs. A session was devoted to each of these two workgroups, comments were elicited from the meeting participants and these workgroups will continue their work. For the standard definition workgroup discussion, meeting participants indicated that follow-up testing often occurs after 12 weeks and this would affect the count of children with elevated blood lead levels. There were concerns voiced about how race and ethnicity are collected and which test result to include when a capillary pair is used to confirm a case.

For the data release workgroup, meeting participants recommended that CDC produce tables that reflect guidelines, for example ages targeted for screening. Another meeting participant commented that it is important to look at smaller areas, such as county level data, to assess areas where lead poisoning is a greater problem. It was also recommended that CDC report a percent change in reaching the target population. One program manager noted that she is often asked to provide an estimate of the number of children who have elevated BLLs in her jurisdiction, and added that reporting the number of children is understood by policy makers, but prevalence may not be as useful a measure when communicating with certain groups.

*Surveillance Data Submission Process and Recommendations* – The process for submitting childhood blood lead surveillance data to CDC was discussed. Meeting participants described how they handle children tested and reported in their state who have addresses in other states. Several participants said they exchange information with surrounding states. One participant mentioned that this sharing process can be hampered by turn over of staff in neighboring states. CDC has been rejecting records if the child's test date is the same as the date of birth, however, several CLPPPs indicated that they do newborn testing.

*Electronic Laboratory Reporting* – An overview of the findings from an electronic laboratory reporting survey was presented. Oregon reported results from a survey of Regions 9 and 10 to gather information about state electronic data interface capacities and blood lead reporting. The findings indicated that a majority of those states surveyed have the ability to receive an HL7 message. The challenge is that only basic information is reliably present and there is wide variation in reporting of other variables. The CLIA regulatory status of the hand-held instrument will change from moderately complex to a "waived test" within the next 2-3 years. This change could impact reporting if more physicians' offices use the instrument. It is important to build reporting infrastructure now. ESA has collaborated with several states to develop and transfer blood lead reporting software, used specifically for reporting results obtained from the ESA LeadCare® portable instrument. Another approach would be to write a program that would improve reporting

from the doctors' offices. Virginia's CLPPP has overcome some laboratory reporting barriers by contacting a few of the larger laboratories. Several laboratories stated that they could do more if there was a state law requiring them to send the data. A formal survey of all laboratories revealed that almost all were willing to and capable of reporting electronically.

*NEDSS* – The National Electronic Disease Surveillance System (NEDSS) was described. CDC is developing NEDSS to integrate data collection systems to transfer appropriate public health, laboratory, and clinical data efficiently and securely over the internet. NEDSS includes tools for electronic data transfer to health departments from health care systems. NEDSS has security standards (i.e., is HIPAA compliant) to maintain public health track record in protecting sensitive data. The initial focus is for infectious diseases, however, lead will become the first non-infectious disease to use NEDSS. A program area module (PAM) will be developed for lead. CLPPPs are encouraged to contact their NEDSS coordinator in their health department.

*Are we collecting the data we need?* – STELLAR has been used by many CLPPPs for patient tracking, however, CDC is supporting the development of a NEDSS module for lead that will replace STELLAR. CDC Lead staff will seek input from the CLPPPs on the design of a Lead PAM. CDC will continue to support/update STELLAR until the NEDSS Lead Module is developed and implemented. Some of the changes to STELLAR will include making the race category OMB compliant; making changes to accommodate the new quarterly report; developing routines to improve data quality; and making modifications to make Medicaid matching easier. There was discussion about whether some new fields should be included in the Lead Module. Some suggestions were whether the child's home had been recently renovated, history of travel outside of the United States, and country of origin. One participant suggested the lead module allow some flexibility in adding new fields that are of interest to particular areas.

*GIS for Evaluation and Research Collaboration with CLPPPs* – The session on geographic information systems (GIS) highlighted the value of using GIS maps to show policy makers and others the areas where young children are likely to be exposed to lead. GIS allows us to identify properties built before 1950 (high risk for lead exposure) to identify where screening should be targeted. It also allows us to evaluate whether high-risk children are being tested. Examples of spatial analysis using CLPPP data were presented. Potential data sources for use in GIS were described. NCEH has purchased state-of-the-art GIS software which will be available on the CDC website to CLPPP user. CDC is planning training for the use of this GIS software.

*Keeping Expectations High* – Dr. Jackson, Director, CDC National Center for Environmental Health, identified several key activities that must be supported by data to reach our elimination goal. First, to help the most children, data must be used to direct resources to areas where there are large numbers of children at risk for lead poisoning. To assess whether we are testing high-risk children, state laws should require all physicians who test children for lead, and laboratories that perform blood lead testing to report all blood lead levels to the state or local health department. It is crucial that we have effective child tracking systems to ensure that children receive appropriate follow-up care. Many children who are tested and found to have elevated blood lead levels are not retested or do not receive appropriate medical care because they move or cannot be contacted. CDC is developing new tracking methods to ensure that children receive the care they need. CDC is developing a new web-based disease reporting system, NEDSS, and childhood lead poisoning will

become the first non-infectious disease included in this national reporting system. It will facilitate timely reporting and improve access within state and local health departments. We must also use geographic information systems to identify areas of greatest need and to evaluate our preventive interventions. GIS can make powerful messages. Because lead is a local problem, partnerships should be developed at the state and local level with staff in housing and programs serving children at risk for lead poisoning. CDC's prevention activities must be enhanced by partnerships with federal agencies such as HUD to help remediate the homes of children with high blood lead levels; EPA to ensure lead regulatory guidance and training and certification; CMS to ensure blood lead tests, and appropriate case management and home inspections for Medicaid eligible children as well as reimbursement, and USDA's WIC Programs to ensure that children are tested for lead and receive appropriate nutritional follow-up. The effectiveness of these partnerships can be evaluated and improved using lead tracking data and linking with other data.

Meeting participants presented their challenges to Dr. Jackson. One problem is that the CLPPPs can find the hazards in the homes of children with elevated blood lead levels, but there is no money to remediate those properties. Some participants voiced frustration with the lack of support from other agencies. For example, one state reported that CMS won't support primary prevention. Another said the state Medicaid agencies say they cannot share blood lead test results with the health department. Others have had trouble working with their housing agencies or WIC programs.

*Medicaid Partnerships* – The session on developing partnerships with Medicaid presented avenues for decreasing the barriers with state agencies in information and data sharing. CLPPPs must take the lead role in establishing a partnership with the State Agencies and others that are working toward the same goal. CLPPPs should look at the big picture of public health infrastructure. To be successful in the elimination of lead in the nation's children by 2010, the CLPPP should build a workforce capacity with the Medicaid Agency through information and data system sharing. This can be accomplished by continuing existing partnerships and identifying new stakeholders. It is helpful to identify a point of contact with the agency. Stay involved and serve on committees. Know your State Lab Director. Find out if the software is comparable with CLPPP's. Establish a Memorandum of Agreement using an informal and/or formal process. Work toward garnering reimbursement as a budget resource to the program and/or the health department. Important partners for collaboration include advocates, state and regional EPSDT Coordinators, the Health Departments and other environmental child health programs that have a common interest in accessing Medicaid information, and the National Resources (Advisory Committee, etc.)

*Medicaid Linking* – The next session focused on implementing Medicaid linking. This presentation discussed CDC's efforts to develop a national report on Medicaid linkage methods and the results from those linkages. The purpose of the national report is to: 1) highlight the different approaches used by state, city and county CLPPPs to link childhood blood lead data with childhood Medicaid data; 2) to highlight the complexities, non-uniformity, strengths and limitations of such linkages; and 3) to report the results of such linkages (i.e., screening and elevated BLL numbers and percentages among Medicaid enrolled children) and compare them with the remaining population (i.e., screening and elevated BLL numbers and percentages among non-Medicaid enrolled children). At least 32 CLPPPs have some type of data sharing with Medicaid, 15 of which have results. The most common variables used to create a match is first name, last name, and date of birth. One

CLPPP's efforts to link surveillance and Medicaid data have increased funding from Medicaid to the CLPPP for Medicaid-eligible children.

*Using Surveillance Data to Guide, Monitor, and Evaluate Your Program* – CDC and CLPPP meeting participants discussed ways to use surveillance data to evaluate CLPPP programmatic activity. After a brief presentation of logic models and their role in developing evaluation measures, the meeting participants broke off into 10 groups discussing how to evaluate various programmatic activities. The small groups wrote suggestions on index cards, and each group presented one or two of their suggestions.

*What would an ideal surveillance system look like?* – The session on the ideal childhood blood lead surveillance system generated considerable discussion. When asked what would be ideal from laboratories, meeting participants mentioned 100% electronic reporting; not missing data; uniform coding, formats and fields, limits of detection; timely reporting; information on the equipment used for the test, such as filter paper or hand-held instrument; an identification number for the person conducting the laboratory test and the person collecting the blood sample; and printed rather than hand written information. There was a suggestion to create a work group to further develop electronic laboratory reporting. Improvements at the health department would include a centralized, web-based database; keeping staff trained; being HIPPA compliant; having high-speed internet access; making data available to people who need it. A written protocol for their surveillance system should outline what to do if the system crashes or the database is corrupt; how to recover data; and importing electronic data. Many participants indicated interest in developing a data management protocol to address data quality assessment and assurance; data security; records retention schedule; data receipt; and data updating.

*Facilitating Communication Between Our Partners and the CDC* – One of the goals of the meeting was to inform CLPPPs about what CDC was doing to improve communication and to learn what CLPPPs perceived as important and effective communication methods. CDC has been working on developing a surveillance profile website so that CLPPPs could update information related to their surveillance system. This will be useful in assessing similarities and differences between CLPPPs that can be useful in moving toward NEDSS or NEDSS compatible systems as well as electronic laboratory reporting. This would require a password that CDC would send to CLPPPs. There is a Lead Listserv that can be used to post questions. The CDC is developing its website to serve as a resource for CLPPPs and others interested in preventing childhood lead poisoning.

*The Role of Surveillance in HITS Projects* – A presentation on CDC's new initiative, High Intensity Targeted Screenings (HITS) described HITS as a part of a three tiered surveillance approach to measure progress towards the 2010 elimination goal and to refine lead poisoning prevention strategies. Data from HITS will be used in conjunction with data from the National Childhood Blood Lead Surveillance System (CBLS) and the National Health and Nutrition Examination Survey (NHANES). HITS is public health in action. It is also a science-based approach to understanding the lead poisoning problem in specific locales. The goals of HITS are to: 1) Identify children missed by routine screening; 2) Improve surveillance and estimate the burden of lead poisoning in a specific locale; 3) Evaluate current screening activities with funded programs; 4) Develop partnerships with other Federal agencies (e.g. EPA, HUD, CMS), and; 5) Increase local

capacity to improve scientific skills and promote targeted screening efforts. The goal of the first Chicago HITS was to find new cases, compare the prevalence of elevated blood lead levels obtained in HITS with city surveillance data, and to assess risk factors for lead exposure among children aged 1-5 years living in two Chicago community areas. The investigation used a cluster survey design sampling strategy involving a blood lead survey (n=539) and a household risk factor questionnaire (n=365). The project identified 327 (61%) previously untested children in these high-risk communities. Twenty-seven percent of all children had blood lead levels  $\geq 10$  Fg/dL compared with 4% nationwide and 7% had BLLs  $\geq 20$  Fg/dL. Programs that are interested in conducting HITS should contact their project officer.

*Environmental Health Tracking: Improving Linking Between Public Health and Environmental Data* – Currently, no systems exist at the state or national level to track many of the exposures and health effects that may be related to environmental hazards. In most cases, existing environmental hazard, exposure, and disease tracking systems are not linked together. Because existing systems are not linked, it is difficult to study and monitor relationships among hazards, exposures, and health effects. The public health tracking network will develop capacity in environmental health within state and local health departments. CDC recently awarded grants to 20 state and local health departments and three Schools of Public Health to begin developing a national environmental health tracking network and to develop capacity in environmental health at the state and local levels. The meeting participants described frustration attempting to share data with EPA and HUD. One problem is that 3-4 different forms are required for environmental issues.

#### Next steps for CDC:

- CDC sent Senator Reid a summary of this meeting, including the challenges CLPPPs encounter and suggestions of what is needed to achieve the national elimination goal
- CDC plans to post the work group draft surveillance definitions and draft data release policy statement on the CDC website so more people can comment.
- CDC will collaborate with existing initiatives to foster development of electronic laboratory reporting for lead.
- The evaluation discussion will be continued after the completion of the 2003 program application period. It should lead to a more organized set of examples of successful strategies for using surveillance data, and guidelines for minimal activities based on what is both possible and practical, especially in using surveillance data to monitor progress towards eliminating childhood elevated blood lead as a public health problem

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